UTAH INBORN METABOLIC ERRORS SURVEY INSTRUCTIONS

Commercial health insurers in Utah who reported at least $1,000,000 in comprehensive hospital & medical business in Utah during 2003 are required to complete and file this survey. All forms necessary to complete the survey are available electronically at: http://www.insurance.utah.gov/hot.html. A copy of the completed survey form should be received by the Utah Insurance Department **by no later than March 16, 2005**. Submissions may also be made via email to jhawley@utah.gov. Failure to file by the deadline may subject your company to the enforcement penalties under Utah Code Annotated (U.C.A.) § 31A-2-308. Any questions on completing this survey form should be directed to Jeff Hawley, Research Analyst, at (801) 538-9684.

This survey is designed to collect data that will allow the Utah Insurance Department to evaluate the current impact of Utah Code Annotated (U.C.A.) § 31A-22-623 "Coverage of inborn metabolic errors" on Utah's commercial health insurance market. All data values reported on the survey form should represent the state of your company as of December 31 (year-end) of the report year.

Data is required for any year that your company had comprehensive hospital & medical insurance (e.g., major medical or hospital & medical) in Utah during 2002, 2003, and 2004. You are required to submit one copy of the survey for each year of data. For the years your company did not have any comprehensive hospital & medical insurance in Utah submit a copy of the completed survey for that year with "NONE" written on it. For example, if your company had comprehensive hospital & medical insurance in Utah during 2002 and 2003, but no business in 2004, then three surveys should be submitted: two with data (report years 2002 and 2003) and one with "NONE" (report year 2004).

Your company was selected for participation in this survey because your company reported at least $1,000,000 in direct insured comprehensive hospital & medical business in Utah during 2003. Please note that direct insured business means business where the insurance company bears the underwriting risk prior to ceding or assumption and should include all Utah residents (even if your company wrote the policy in another state and the insured member later moved into Utah). It does not include any administrative only (e.g., ASO or ASC) or any type of self-funded business. The survey uses the same definition of "comprehensive hospital & medical insurance" as is used in the NAIC Financial Statement. Only data on comprehensive hospital & medical insurance (e.g., major medical or hospital & medical) is needed. Therefore, any accident & health business that does not meet the NAIC criteria for comprehensive hospital & medical (such as medical only, dental only, vision only, stop loss, disability income, credit A&H, long-term care, and Medicare supplement, as well as Medicare & Medicaid or self-funded) should be excluded.

RECOMMENDED METHODOLOGY

First, review your claim processing procedures for adjudicating claims for metabolic dietary products. These claims may be submitted under UB-92, HCFA-1500, or pharmacy claim forms. They may be billed under HCFA codes such as Y-codes, B-codes, or S-codes under a major medical benefit as well as through NDC format codes under a pharmacy benefit. The Utah Insurance Department attempted to find a standard set of codes under which these claims would be billed, however, our information so far suggests that there is not a standard method being used by all Utah health insurers. Although a common standard using Y-codes was developed by the Utah Health Information Network (UHIN) and adopted by rule (see R590-194 "Coverage of Dietary Products for Inborn Errors of Amino Acid or Urea Cycle Metabolism"), ad hoc inquires to health insurers suggest that few commercial health insurers are using these codes to process these claims. This is because the Y-codes developed for this purpose are not HIPAA compliant (no state specific codes). A new common standard is currently being developed with UHIN, but is not applicable for the data period being reviewed by this survey.

Second, limit all data extraction to Utah comprehensive hospital & medical insurance business as defined in the NAIC annual statement and reported on the Utah Accident & Health Survey.

Third, for the purposes of this survey, a member will be classified as having an inborn metabolic disorder if the member has either a claim with a diagnosis code for an inborn metabolic error of amino acid or urea cycle metabolism (see diagnosis codes listed in the Excel spreadsheet "Utah Inborn Metabolic Errors Survey.xls") or a claim for a metabolic dietary product used in the treatment of inborn metabolic errors of amino acid or urea cycle metabolism (see the list of NDC format codes for protein formulas and the list of HCPCS codes for medical foods/formulas listed in the Excel spreadsheet "Utah Inborn Metabolic Errors Survey.xls") at any time between January 1 and December 31 of the report year. This method will capture the members most likely to use the metabolic dietary products described in U.C.A. § 31A-22-623.

It is necessary that both the diagnosis codes and the metabolic dietary product codes be used, as using either method alone may miss some members with an inborn metabolic disorder. Please make every effort to identify these members, as they are relatively rare. The incidence rate for inborn metabolic disorders is very low. For example, the incident rate for the most common metabolic disorder, Phenylketonuria (PKU), is approximately 1 in 10,000 and if the incidence rate is applied to Utah's population the estimated prevalence is less than 300 individuals per year. The Utah Metabolic Clinic currently tracks around 115 individuals (age 21 or younger) with one of four metabolic disorders, but their agency does not track all types of metabolic disorders or individuals older than 21. Current studies suggest that the overall prevalence of all inborn metabolic disorders is less than 1 in 5,000 persons.

Fourth, use the population of members with an inborn metabolic disorder and the list of NDC codes for protein formulas and the list of HCPCS codes for medical foods/formulas to extract the information requested on the survey form (see the Excel spreadsheet "Utah Inborn Metabolic Errors Survey.xls") from your paid claims database.

If you have any questions regarding the completion of this survey, please contact Jeff Hawley, Research Analyst, at 801-538-9684.

COLUMN DEFINITIONS FOR PAGE 1

AGES 0 TO 17:	Enter the total number of member months for all fully insured members in each row category that are 17 years old or younger as of December 31 of the report year (see CUMULATIVE MEMBER MONTHS for definition).
AGES 18 TO 34:	Enter the total number of member months for all fully insured members in each row category that are between 18 and 34 years old as of December 31 of the report year (see CUMULATIVE MEMBER MONTHS for definition).
AGES 35 TO 49:	Enter the total number of member months for all fully insured members in each row category that are between 35 and 49 years old as of December 31 of the report year (see CUMULATIVE MEMBER MONTHS for definition).
AGES 50 TO 64:	Enter the total number of member months for all fully insured members in each row category that are between 50 and 64 years old as of December 31 of the report year (see CUMULATIVE MEMBER MONTHS for definition).
AGE 65 OR OLDER:	Enter the total number of member months for all fully insured members in each row category that are 65 years old or older as of December 31 of the report year (see CUMULATIVE MEMBER MONTHS for definition).
ALL AGES:	Enter the total number of member months for all fully insured members in each row category for all ages. This column (VI) should be the total of the previous five columns (I through V) (see CUMULATIVE MEMBER MONTHS for definition).
CUMULATIVE MEMBER MONTHS:	Enter the cumulative year-end member months for each category. To calculate member months, first count the number of insured members during each month of the year. This produces 12 member counts (one for each month). Then sum total all 12 member counts. This total is the cumulative member months for the year. For example, if your company had 10 insured members during each of the 12 months of the year, the cumulative member months would be calculated as follows: 10 members x 12 months = 120 member months.

ROW DEFINITIONS FOR PAGE 1

The following row definitions provide the ICD-9 medical diagnosis codes for the 270 series “Disorders of amino-acid transport and metabolism” as defined by the International Classification of Diseases (9th Revision). These codes exclude abnormal findings without manifest disease (790.0-796.9), disorders of purine and pyrimidine metabolism (277.1-277.2), and gout (274.0-274.9). These codes have been identified as the conditions most likely to use the metabolic dietary products that commercial health insurers are required to cover under U.C.A. § 31A-22-623. However, it is possible for some members to have paid claims for metabolic dietary products, but not have a diagnosis code for an inborn metabolic disorder. Therefore, a category for members with claims for medical foods and protein formulas without a 270 series diagnosis code has been included. Please report complete data (see column definitions) for each row category.

Dx 270.0:	Disturbances of amino-acid transport.
Dx 270.1:	Phenylketonuria [PKU].
Dx 270.2:	Other disturbances of aromatic amino-acid metabolism.
Dx 270.3:	Disturbances of branched chain amino-acid metabolism.
Dx 270.4:	Disturbances of sulphur-bearing amino-acid metabolism.
Dx 270.5:	Disturbances of histidine metabolism.
Dx 270.6:	Disorders of urea cycle metabolism.
Dx 270.7:	Other disturbances of straight-chain amino-acid metabolism.
Dx 270.8:	Other specified disorders of amino-acid metabolism.
Dx 270.9:	Unspecified disorder of amino-acid metabolism.
Dx 655.43:	Suspected damage to fetus from other disease in the mother – toxioplasmosis (i.e., Maternal PKU).
MEDICAL FOOD/ FORMULA CLAIMS W/O DX:	For members who have medical food, enteral, and protein formula claims, but for some reason do not have an inborn metabolic disorder diagnosis code listed.
TOTAL (ALL Dx 270.0-270.9, 655.43 + CLAIMS W/O Dx):	Total members for all diagnosis codes listed previously, specifically, 270.0 to 270.9, plus 655.43, as well as members with medical food/formula claims without diagnosis code.
ALL COMPREHENSIVE MEMBERS:	Total members with comprehensive hospital & medical insurance in Utah.

COLUMN DEFINITIONS FOR PAGE 2

Dx 270.1 (PHENYLKETONURIA):	Enter data for all members with diagnosis code 270.1 “Phenylketonuria [PKU]”. Exclude all others.
Dx 655.43 (MATERNAL PKU):	Enter data for all members with diagnosis code 655.43 “Suspected damage to fetus from other disease in the mother – toxioplasmosis (i.e., Maternal PKU). Exclude all others.
Dx 270.0, 270.2 through 270.9 (ALL OTHER DX):	Enter data for all members with any other diagnosis code for an inborn metabolic error, specifically, codes 270.0, 270.2, 270.3, 270.4, 270.5, 270.6, 270.7, 270.8, and 270.9. Exclude 270.1, 655.43, and Medical Food/Formula without Dx.
MEDICAL FOOD/FORMULA WITHOUT DX:	Enter data for all members with claims for medical foods and protein formulas for the treatment of an inborn metabolic error of amino acid and urea cycle metabolism, but do not have a diagnosis code listed for an inborn metabolic error. Exclude all others.
TOTAL UNDER ALL MEMBERS WITH INBORN METABOLIC DISORDER:	Enter data for all members in the four previous columns (i.e., columns I, II, III, and IV.).
TOTAL UNDER ALL COMPREHENSIVE POLICIES:	Enter data for all members under all comprehensive health insurance policies in Utah regardless of diagnosis code (i.e., all members with or without an inborn metabolic error). Membership data reported in this column should balance (within reasonable limits) to the Utah business reported on the Utah Accident & Health Survey and NAIC Financial Statement.

ROW DEFINITIONS FOR PAGE 2

Membership:

NUMBER OF INSURED MEMBERS:	Enter the number of fully insured members for each category. The number of insured members should equal the number of certificate holders plus dependents enrolled as of December 31 of the report year. For example, if there were 150 members who participated in your plan during the year, but only 100 members were currently enrolled as of December 31, report the number of insured members as 100.
CUMULATIVE MEMBER MONTHS:	Enter the cumulative year-end member months for each category. To calculate member months, first count the number of insured members during each month of the year. This produces 12 member counts (one for each month). Then sum total all 12 member counts. This total is the cumulative member months for the year. For example, if your company had 10 insured members during each of the 12 months of the year, the cumulative member months would be calculated as follows: 10 members x 12 months = 120 member months.

Medical Food Claims (S9435 only):

NUMBER OF CLAIMS:	Measure of medical food utilization. Includes all claims billed for medical foods (usually low protein modified foods) used specifically in the treatment of inborn metabolic errors of amino acid or urea cycle metabolism as defined in R590-194, and billed under HCPCS code S9435 “Medical foods for inborn errors of metabolism” as a medical claim (see the “HCPCS codes for Medical Claims” worksheet in “Utah Inborn Metabolic Error Survey.xls” for the specific medical codes to be used). Utilization is measured by counting the number of unique dates of service. For example, each unique date of service equals one medical food claim. Only claims for medical foods using a HCPCS S9435 code are reported here. Exclude any protein formula claims, as these will be reported separately.
INSURER PAID:	Enter the total dollar amount of all medical food claims that the insurance company is responsible for (after applying coinsurance, copays, or deductibles). This is the portion of the claim usually defined as “paid claims” on the NAIC annual statement. Only claims for medical foods using a HCPCS S9435 code are reported here.
INSURED PAID:	Enter the total dollar amount of all medical food claims that the insured member is responsible for. This includes any coinsurance, copays, or deductibles. This portion of the claim is usually omitted from “paid claims” as defined by the NAIC annual statement (as the insurer does not pay this, the member does). Only claims for medical foods using a HCPCS S9435 code are reported here.

Enteral Formula Claims (B codes only):

NUMBER OF CLAIMS:	Measure of protein formula utilization billed as an enteral formula claim. Includes all claims billed for protein formula (used as an enteral formula) used specifically in the treatment of inborn metabolic errors of amino acid or urea cycle metabolism as defined in R590-194, and billed under HCPCS B codes as a medical claim (see the "HCPCS codes for Medical Claims" worksheet in "Utah Inborn Metabolic Error Survey.xls" for the specific medical codes to be used). Utilization is measured by counting the number of unique dates of service. For example, each unique date of service equals one enteral formula claim. Only protein formula claims using HCPCS B codes are reported here. Exclude any protein formula claims billed using a NDC format code, as these will be reported separately (see "Protein Formula Claims")
INSURER PAID:	Enter the total dollar amount of all enteral formula claims that the insurance company is responsible for (after applying coinsurance, copays, or deductibles). This is the portion of the claim usually defined as "paid claims" on the NAIC annual statement. Only protein formula claims using a HCPCS B code are reported here.
INSURED PAID:	Enter the total dollar amount of all enteral formula claims that the insured member is responsible for. This includes any coinsurance, copays, or deductibles. This portion of the claim is usually omitted from "paid claims" as defined by the NAIC annual statement (as the insurer does not pay this, the member does). Only protein formula claims using a HCPCS B code are reported here.

Protein Formula Claims:

NUMBER OF SCRIPTS:	Measure of protein formula utilization. Includes all claims paid for protein formulas used specifically in the treatment of an amino acid or urea cycle metabolic disorder as defined in R590-194, and billed under a NDC format code as a pharmacy claim (see the "NDC Codes for Protein Formulas" worksheet in "Utah Inborn Metabolic Error Survey.xls" for the specific NDC format codes to be used). Utilization is measured by counting the number of prescriptions (count one script per unique date of service regardless of pill count or volume) submitted for protein formula.
INSURER PAID:	Enter the total dollar amount of all protein formula claims that the insurance company is responsible for (after applying coinsurance, copays, or deductibles). This is the portion of the claim usually defined as "paid claims" on the NAIC annual statement. Only claims for protein formula billed using a NDC format code are reported here.
INSURED PAID:	Enter the total dollar amount of all protein formula claims that the insured member is responsible for. This includes any coinsurance, copays, or deductibles. This portion of the claim is usually omitted from "paid claims" as defined by the NAIC annual statement (as the insurer does not pay this, the member does). Only claims for protein formula billed using a NDC format code are reported here.

Pharmacy Claims:

NUMBER OF SCRIPTS:	Measure of pharmacy utilization. Includes all claims paid under the insured member's pharmacy benefit. Utilization is measured by counting the number of prescriptions (count one script per unique date of service regardless of pill count or volume) written by all health providers.
INSURER PAID:	Enter the total dollar amount of the pharmacy claims under all comprehensive health insurance policies that the insurance company is responsible for (after applying coinsurance, copays, or deductibles). This is what is usually defined as "paid claims" on the NAIC annual statement.
INSURED PAID:	Enter the total dollar amount of the pharmacy claims under all comprehensive health insurance policies that the insured member is responsible for. This includes any coinsurance, copays, or deductibles. This is usually omitted from "paid claims" as defined by the NAIC annual statement (as the insurer does not pay this, the member does).

Total Comprehensive Claims:

INSURER PAID:	Enter the total dollar amount of all claims under comprehensive health insurance policies that the insurance company is responsible for (after applying coinsurance, copays, or deductibles). This is what is usually defined as "paid claims" on the NAIC annual statement. The total paid claims reported here should balance (within reasonable limits) to the Utah business reported on the Utah Accident & Health Survey and NAIC Financial Statement.
INSURED PAID:	Enter the total dollar amount of all claims under comprehensive health insurance policies that the insured member submitting the claim is responsible for. This includes any coinsurance, copays, or deductibles. This is usually omitted from "paid claims" as defined by the NAIC annual statement (as the insurer does not pay this, the member does).